

## Protecting Patient Privacy in Narratives: The Lifespan-Brown Checklist for Appropriate Use of Patient Narratives

WILLIAM RAFELSON,<sup>a,b</sup> JANE BRUNO,<sup>c</sup> DON S. DIZON<sup>a,b,c</sup>

<sup>a</sup>Division of Hematology-Oncology, Department of Medicine, Alpert Medical School of Brown University, Providence, Rhode Island, USA; <sup>b</sup>Lifespan Cancer Institute, Providence, Rhode Island, USA; <sup>c</sup>Rhode Island Hospital, Providence, Rhode Island, USA

Disclosures of potential conflicts of interest may be found at the end of this article.

Self-reflection is an important aspect of medicine, and writing and publishing these narratives can have a number of positive effects, including a greater understanding of the medical humanities for the reader, as well as increased empathy for the caregiver [1]. Stories about medical practice also provide a means of bonding and can shape conversations that we have, as individuals and as part of the medical profession [2]. Top medical journals have standing calls for such narrative submissions, including The Art of Oncology section in the *Journal of Clinical Oncology*, A Piece of My Mind in *JAMA*, and Narratives in Oncology in *The Oncologist*, to name just a few.

Authors are no longer restricted to editorial decisions in journals or contracts from publishing houses to have their stories published. In the digital era, anyone can write and publish on the internet, whether it is as blogs, microblogs (tweets), or other forms of expression. But whether our writing is published in traditional or new media, the risk of breaching patient confidentiality remains a particular concern. As an example, a prominent legal case in Rhode Island in 2011 focused on an emergency room physician who posted on Facebook about a patient seen in the context of a busy shift [3]. Although the author did not name the patient, identifying characteristics and circumstances of the event were sufficient for the patient to learn that it was about him. Ultimately, the physician was reprimanded by the state medical board and had to relinquish her hospital position. The situation is not unique; a separate study that included over 270 blogs revealed that more than 15% included enough information to identify a patient [4].

The question, then, is how can we support narratives written by clinicians regardless of the forum in a way that promotes reflection without breaching the confidentiality inherent within the patient-provider relationship?

In our review of the literature, we found no practical guidelines for would-be authors to write narratives while protecting patient privacy. We did find opinions on what should be done. On one end of the spectrum, some argue one should always obtain consent from any patient about whom you are writing. Charon wrote that the rationale for obtaining consent is that “even though names, dates, and similar information might be

changed, the affiliation of the author points to a given institution, and the highly singular clinical details of illness make patients recognizable, even if only to themselves, their families and those who work in the author’s institutions... the trustworthiness of all physicians would be compromised if patients had to worry that their doctors would broadcast information about them in print without their permission.” [5]. On the other end are others who support the concept of de-identification, which is the practice of anonymizing a patient to eliminate the chance of discovery by others (or the patient him- or herself). This is the practice of one of the authors (D.D.) and is widely adopted for the publication of case reports [6].

We believe that when it comes to writing about patient-provider experiences, both opinions warrant examination. In response, we have constructed the following checklist for creative writing of the patient experience, incorporating both when de-identification is appropriate and when writing without proper consent should be avoided. This paper discusses Protected Health Information (PHI) and the Health Insurance Privacy and Portability Act (HIPAA), also known as the federal Privacy Rule (45 CFR Part 160 and Part 164, Subparts A and E). We use these guiding documents to construct the Lifespan-Brown checklist for Narratives.

### WHAT CONSTITUTES PHI

The HIPAA Privacy Rule imposed national standards to control the use and disclosure of PHI, which is broadly defined as any health information that is collected from the patient, or created, or received, that relates to the past, present, or future physical or mental health or condition of a patient that could potentially identify that individual. As stated on the Department of Health and Human Services website, the Privacy Rule “protects all ‘individually identifiable health information’ held or transmitted by a covered entity or its business associate, in any form or media, whether electronic, paper, or oral.” [7].

### THE HIPPA DEFINITION OF DE-IDENTIFICATION

The standard for de-identification of PHI is found in the HIPAA Privacy Rule at 45 CFR Section 164.514(a). The rule

states: “health information that does not identify an individual and with respect to which there is no reasonable basis to believe that the information can be used to identify an individual is not individually identifiable health information.” Section 164.514(b) then sets forth 18 identifiers (Table 1) that, at a minimum, must be stripped from patient information (and information of relatives, employers, and household members) in order for such information to be considered “de-identified.” Writers who do not have patient consent must remove these 18 identifiers and should exercise additional caution when dealing with a rare illness or a patient in the public eye, because excision of additional detail might be necessary to avoid identifying such a patient in practice. In short, it is not sufficient to satisfy only oneself as an author that sufficient steps have been taken to address confidentiality of PHI. In our opinion, it is advisable that authors seek feedback on potential narratives from another person. This should be someone with editorial experience, or at the very least, someone embedded within your institution’s communication department. The goal of such collaborations should not be to censor or replace the author’s voice but rather to ensure privacy protections have been sufficiently undertaken. We believe that our checklist can provide the objective ground from which all parties can work.

#### THE BROWN-LIFESPAN CHECKLIST FOR NARRATIVES

To create this checklist, Brown Medicine representatives in the Division of Hematology and Oncology (D.D. and W.R.) worked closely with Lifespan’s Department of Marketing and Communications (J.B.) and Physician Affairs (J.M.). Everyone was provided with the checklist and had the opportunities to comment and modify each element. The resulting document reflects consensus among all parties (Table 2).

#### Have All Demographic Identifiers Been Changed or Removed?

In the absence of written permission from the patient, all demographic identifiers should be removed from any narrative, including the patient’s name, date of birth, and geographic location (any smaller than the state). This is the first step for de-identification and should be universally followed. It is important to understand that although one’s date of birth should never be used, for patients under the age of 90, one can state the *age* of the patient being written about and can write about what *state* and *country* the patient resides in; anything more would not meet the standards set in the Privacy Rule.

Another method of de-identification would be to depict composite characters (i.e. writing about a character that is made up of two or more patients) [I think you should define what you mean here for clarity] in one’s narrative. If done, it is important to provide appropriate notice to the reader that this is the case. A simple method commonly employed is to prominently include a disclaimer such as “Names and details have been changed to protect privacy.” However, the author should give careful thought to this strategy, as some medical journals forbid it; for example, JAMA, in its guidelines to authors [8], states, “Omitting data or making data less specific to deidentify

**Table 1.** The 18 identifiers, as defined by the Health Insurance Portability and Accountability Act (HIPAA)

Category	PHI element (no. of 18 total)
Demographics	(1) Names (2) Geographic subdivisions <b>smaller</b> than a state (including street address, city, county, precinct, ZIP code <sup>a</sup> ) (3) Social security numbers (4) All elements of dates (except year) for dates related to an individual <sup>b</sup> (5) Certificate/license numbers (6) Vehicle identifiers and serial numbers (includes license plate numbers)
Contact information	(7) Telephone number(s) (8) Fax numbers (9) Electronic mail addresses
Medical identifiers	(10) Medical record numbers (11) Health plan beneficiary numbers
Financial information	(12) Account numbers
Mobile and web-based access information	(13) Device identifiers and serial numbers (14) Web universal locators (URLs) (15) IP address numbers
Physical information	(16) Biometric identifiers (includes finger and voiceprints) (17) Full-face photographic image <sup>c</sup>
Miscellaneous	(18) Any other unique identifying number, characteristic, or code

<sup>a</sup>Use of the first three digits of a ZIP code is allowable.

<sup>b</sup>Prohibited dates include birth date, admission date, discharge date, date of death, all ages over 89, and all elements of date (including year) indicative of such age, except that such ages and elements may be aggregated into a single category of age 90 or older.

<sup>c</sup>Also include any comparable images.

Abbreviations: IP, Internet Protocol; PHI, Protected Health Information.

patients is acceptable, but changing any such data is not acceptable. Fictional or composite accounts are not permitted.”

#### Have You Ensured There Is No Contact Information for the Patient?

Although this sounds intuitive, it bears specific mention not because one would specifically include this information in a narrative, but because of what may occur following publication. Readers of a narrative may be interested in obtaining more information on a specific case, and as such, it is not inconceivable to receive a request to contact the subject, whether the request comes in private or via a social media channel. Under no circumstances should the contact information be disclosed, and this is particularly important if the narrative was written without the explicit consent of the subject.

#### Is the Narrative Devoid of Any Medical Identifiers? Are You Certain No Account Numbers are Included?

In our combined opinion, there is no rational reason to include any kind of medical or financial identifier in the context of a patient narrative. As such, both should be completely avoided.

**Table 2.** The Lifespan-Brown Checklist for Patient Narratives

Element	Yes	No
1. Have all demographic identifiers been changed or removed (PHI 1–6)?	<input type="checkbox"/>	<input type="checkbox"/>
2. Have you ensured there is no contact information (PHI 7–9) for the patient?	<input type="checkbox"/>	<input type="checkbox"/>
3. Is the narrative devoid of any medical identifiers (PHI 10, 11)?	<input type="checkbox"/>	<input type="checkbox"/>
4. Are you certain no account numbers (PHI 12) are included?	<input type="checkbox"/>	<input type="checkbox"/>
5. Have you ensured there is no web-related information that might identify the patient in your piece (PHI 13–15)?	<input type="checkbox"/>	<input type="checkbox"/>
6. Are you sure you are not including identifying physical information (PHI 16, 17)? <sup>a</sup>	<input type="checkbox"/>	<input type="checkbox"/>
7. Are you sure there are no unique identifying numbers, characteristics (physical or otherwise), or codes (PHI 18) used?	<input type="checkbox"/>	<input type="checkbox"/>

To be completed by the author and a peer reviewer from the author's organization.

A "Yes" answer for all elements meets our criteria for de-identification. Otherwise, the narrative should be rewritten.

<sup>a</sup>Only acceptable with the written permission of the patient.

Abbreviation: PHI, Protected Health Information, corresponding to the numbered PHI elements list in Table 1.

### Have You Ensured There Is No Web-Related Information That Might Identify the Patient in Your Piece?

In the era of social media, patients may be active participants on sites such as Facebook and Twitter. As a result, there may be a temptation to include their username (or handles) in the context of *writing* a narrative or *publicizing* the piece on web-based channels. This too would be a violation of the Privacy Standard because it would link the patient to the narrative even if unintentionally. Therefore, abundant caution should be exercised if the author intends to publish and/or push his pieces on social media where both patient and provider are online.

### Are You Sure You Are Not Including Identifying Physical Information?

Unless the patient has given written permission to pursue a narrative, the use of photographs that depict a patient by

face, tattoo, scar, or any other identifying trait must be avoided. The description of rare physical features as above should also be avoided, as readers may be able to identify the patient with the words alone. It is worth noting that permission to write is *not* synonymous with permission to use pictures. We suggest consulting with your institution's marketing team prior to publication if you intend to supplement a narrative with identifying pictures or other media.

### Are You Sure There Are No Unique Identifying Numbers, Characteristics (Physical or Otherwise), or Codes Used?

Although broad in scope, it is important that the author ensure no other identifying information is contained in the narrative. An example of this is the inclusion of the patient's primary caregiver in a narrative, either by name or by description, which may include physical features, both of which could indirectly lead to the identification of the patient. Importantly, this extends to writing when it involves patients with a rare illness or patients who are also public figures. The potential risks that underlie such situations may not be intuitive to the author, which argues once more for authors to work closely with others not directly involved in writing.

### CONCLUSION

Despite great advances in medicine and precision oncology, our profession remains an art, built on unique experiences and the clinician-patient relationship. Just as case reports have value for the clinician in making difficult clinical decisions in patients with rare syndromes, so do narrative pieces hold value for patients and caregivers who are searching for meaning and closure in their dealings with both illnesses and each other. Narrative passages are a part of the artful expression of clinicians and should be encouraged. Here, we provide a checklist for potential authors to use to preserve patient confidentiality when constructing patient stories, in a way to minimize risks to the patient, the author, and to the institution.

### DISCLOSURES

The authors indicated no financial relationships.

### REFERENCES

1. Lemay M, Encandela J, Sanders L et al. Writing well: The long-term effect on empathy, observation, and physician writing through a residency writers' workshop. *J Grad Med Educ* 2017;9:357–360.
2. Steensma DP. Stories we tell one another: Narrative reflection and the art of oncology. *Am Soc Clin Oncol Educ Book* 2013.
3. Conaboy C. For doctors and hospitals, social media a tricky case. *The Boston Globe*. April 20, 2011.
4. Lagu T, Kaufman EJ, Asch DA et al. Content of weblogs written by health professionals. *J Gen Intern Med* 2008;23:1642–1646.
5. Charon R. Narrative medicine: Form, function, and ethics. *Ann Intern Med* 2001;134:83–87.
6. Sun Z. Tips for writing a case report for the novice author. *J Med Radiat Sci* 2013;60:108–113.
7. HHS Office of the Secretary, Office for Civil Rights, and OCR. Summary of the HIPAA Privacy Rule. Available at [www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html](http://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html). Accessed October 3, 2018.
8. JAMA Network. Instructions for authors. Available at <https://jamanetwork.com/journals/jama/pages/instructions-for-authors>. Accessed October 3, 2018.